



Position Paper #25

Abortions for Genetic Reasons

Background

As part of routine prenatal care, pregnant ciswomen and transgender people in Canada are offered an ultrasound scan to look for fetal anomalies. While they may opt for extensive prenatal screening, some may choose testing for other genetic diseases based on their particular risk factors (maternal age, obesity, substance abuse, medication use, family history).¹

Over the past several years, both genetic testing and prenatal diagnosis have progressed and become increasingly sophisticated. Prenatal testing is available for everything from neural tube defects and Down Syndrome to DiGeorge syndrome, Tay Sachs disease, and hemoglobinopathies. The spectrum of disease being tested for ranges from mild to severe disability and early death as in Tay Sachs disease.²

The purpose of prenatal testing is to provide people with as much information as possible regarding their pregnancy and the health of their fetus so they can make an informed choice. Such information should not be withheld because doctors can be held liable via a wrongful birth lawsuit if they do not inform a pregnant patient of detected abnormalities that result in the birth of a disabled child.³ However, it is crucial that healthcare providers approach the issue with sensitivity, so that the lives

¹ The number of scans and screenings varies based on the province (though in provinces where it is not covered, a patient can pay a private company for the screening). In Ontario, for example, screening in the form of an Integrated prenatal screen (IPS) is a blood test and ultrasound between weeks 11-13, then another blood test between week 16-20, with results provided by 18 weeks. Other options are the non-invasive prenatal test (NIPT or Harmony). The latter is only provided under Ontario OHIP for those who screen positive for IPS or if they are over 40 years old. These screenings are elective.

² Canadian College of Medical Geneticists, Society of Obstetricians and Gynaecologists of Canada. *Canadian guidelines for prenatal diagnosis – techniques of prenatal diagnosis*. No. 105. (June 2001.) <https://sogc.org/wp-content/uploads/2013/01/105E-CPG2-July2001.pdf>

³ a) Arndt v. Smith (1994), 21 C.C.L.T. (2d) 66 (B.C.S.C.); Arndt v. Smith (1997), 148 D.L.R. (4th) (S.C.C.); <http://casebrief.me/casebriefs/arndt-v-smith/>.
b) E. Nelson and T. Caulfield, “You Can’t Get There From Here: A Case Comment on Arndt v. Smith,” University of British Columbia Law Review, Vol. 32 (1998), p. 353; Nelson E and G Roberston. Liability for Wrongful Birth and Wrongful Life. *Canadian Journal of Policy Research (isuma)*. Autumn 2001, Vol 2, No 3.
c) Krangle v. Brisco, 1 SCR 205. (2002) <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1946/index.do>

of people with disabilities are not inadvertently devalued. For example, the language used to describe genetic screening should reflect the social and ethical implications of screening. Too often, a medical model of disability presents disability as something abnormal that needs to be “fixed,” when it should never be presented as a poor outcome.

Pregnant people and their families do need to be prepared for the arrival of an affected child (for example, ensuring delivery in a tertiary care centre if the fetus has a major cardiac anomaly), or to make decisions regarding continuing with or terminating a pregnancy in which the fetus has a severe genetic problem. The Ontario Association of Midwives explains:⁴

“From the onset, clients should be fully informed of the difference between screening for life-threatening anomalies, screening for treatable conditions for which early discovery could affect the plan of care, and screening for conditions such as Down syndrome, which do not preclude the possibility of a healthy, active and satisfying life. Clients should be clearly informed of the goals of genetic screening and of potential further testing and treatment options, including an explanation of the conditions for which no treatment exists and under what circumstances a termination of pregnancy may be offered.”

In Canada, most abortions for reasons of fetal disorder or anomaly occur before 20 weeks’ gestation. A few occur up to about 23 weeks, generally only when the fetus is gravely impaired. Very rarely, abortions may be done during the third trimester in cases of lethal fetal abnormality, where the fetus cannot survive after birth.

Response of Advocates for the Rights of the Disabled

Some members of the disabled community and advocates for the rights of the disabled have equated abortion for genetic reasons with eugenics. They often attempt to argue false statistics, such as “the termination rate is as high as 92 per cent”, which is entirely unproven, as the reasons for abortion are not tracked.⁵ They also try to argue that the non-invasive tests introduced in the last five years will encourage more people to have abortions, conveniently forgetting that morphology ultrasounds have been provided for the last twenty years.⁶ Some feel that allowing abortions based on genetic testing devalues the lives of disabled people and implies that living with a disability is inferior to living without one. ARCC disagrees with this interpretation.

⁴ Association of Ontario Midwives. June 2017. *Prenatal Genetic Screening*.
<https://www.ontariomidwives.ca/prenatal-genetic-screening>

⁵ <http://www.ctvnews.ca/down-syndrome-families-worry-about-new-prenatal-tests-1.617292>

⁶ Tied to footnote 1, the 18-22 week ultrasound, which most people equate to the “determination of sex” ultrasound, is in truth a morphology ultrasound that is a detailed look at a fetus’ body and organs to determine Down Syndrome as well as cleft palate and heart defects. Proponents of the “eugenics” argument often forget that we have always checked for these disorders since ultrasound has been available.

ARCC-CDAC Position

The issue of abortion for genetic reasons is not about eugenics or discrimination against disabled people. It is about a pregnant person's ability and preparedness to bear and raise a disabled child, or any child. It is about a personal choice based on the particular circumstances and context of one's life. It is not different from the right to decide about any other pregnancy. Only the pregnant person can decide what to do, because they must bear (and raise) the child. To presume the right of a disabled fetus, or any other fetus, to survive, presumes the obligation of the person to continue the pregnancy and care for the resulting child, and negates their autonomy and rights.

In Canada, women and transgender people do not have to provide a reason to obtain an abortion, since abortions are available upon request. Also, being pro-choice means supporting people's right to decide whether or not to continue a pregnancy, for whatever reason, as "a right includes the freedom to use it in ways that others find distressing"⁷. Moreover, a woman's constitutional right to choose abortion does not stop as soon as she becomes pregnant with a child with a genetic disorder. In fact, this situation is a widely-accepted moral justification for abortion, even by anti-choice people, because bringing a severely ill or disabled child into the world has momentous and lifelong consequences for everyone involved.

Being disabled, in and of itself, is not necessarily related to the quality and importance of life. Once born, the disabled have rights like everyone else, and very often lead full, productive lives. However, there is still significant stigma and marginalization associated with disability, and serious barriers to equality persist throughout society for those living with disabilities.⁸ In addition, severe genetic defects or illnesses can impose a poor quality of life on people, including chronic pain or hardship. Many disabled people, especially the severely disabled, depend upon the care of others. Such care consumes substantial time and resources on the part of the caregiver. It can also involve much heartache and trauma, especially where a child's life may be cut tragically short because of the illness or disability

Pregnant parents are the only ones in a position to evaluate what is in the best interest of themselves and their potential child. The most loving and responsible parents will consider all options and circumstances and make the wisest choice for themselves, and their family. Society should not compel people to forfeit their own rights (or life) to save the life of another, nor should society encourage people to terminate a pregnancy on the grounds of disability. Such choices must be made voluntarily on the basis of complete information presented without bias.

⁷ Pollitt, Katha. *Pro: Reclaiming Abortion Rights*. (Picador, 2014).

⁸ Ontario Human Rights Commission. June 2016. *Policy on ableism and discrimination based on disability*. <http://www.ohrc.on.ca/en/policy-ableism-and-discrimination-based-disability>